

Problems With Access to Dental Care for Medicaid-Insured Children: What Caregivers Think

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Dental disease is the most common health problem affecting children in the United States.^{1,2} Dental caries, the most prevalent type of dental disease in children, occurs more often in disadvantaged children than in others, but even those with public insurance have great difficulty gaining access to primary dental care services.¹⁻⁴ Fewer than 1 of every 5 children enrolled in Medicaid use preventive services in a given year.¹⁻⁴ Worse yet, fewer Medicaid-insured children receive comprehensive dental care beyond the initial preventive visit.¹

In North Carolina, only 12% of Medicaid-insured children aged 1 to 5 years had a preventive visit in 1998.⁵ Untreated dental decay is present in 25% of all children entering kindergarten. Among kindergarten students, 30% of children account for about 95% of all tooth decay, and among fifth-grade students, 15% of children account for about 80% of all tooth decay. Typically, these children with untreated tooth decay are from families of lower socioeconomic status and are eligible for Medicaid.⁵

Numerous studies on access to dental care for Medicaid-insured children have been completed, including those of dentists, who consistently provide 3 major reasons for their lack of participation in the Medicaid program: low reimbursement rates, broken appointments and patient noncompliance, and burdensome paperwork associated with Medicaid.²⁻⁵ A recent study of front-office personnel in dental offices revealed that their attitudes and beliefs have a negative impact on caregivers' getting dental care for their Medicaid-enrolled children.⁶ Very few studies have, however, solicited information from caregivers of Medicaid-insured children. What little published information exists is derived from 3 closed-ended questionnaire surveys, all published as agency reports.⁷⁻⁹ Participants in these surveys typically cited difficulties in finding a dentist and scheduling appointments, long waiting times, and transportation problems.

Objectives. This study aimed to gain insight into the experiences, attitudes, and perceptions of a racially and ethnically diverse group of caregivers regarding barriers to dental care for their Medicaid-insured children.

Methods. Criterion-purposive sampling was used to select participants for 11 focus groups, which were conducted in North Carolina. Seventy-seven caregivers of diverse ethnic and racial backgrounds participated. Full recordings of sessions were obtained and transcribed. A comprehensive content review of all data, including line-by-line analysis, was conducted.

Results. Negative experiences with the dental care system discouraged many caregivers in the focus groups from obtaining dental services for their Medicaid-insured children. Searching for providers, arranging an appointment where choices were severely limited, and finding transportation left caregivers describing themselves as discouraged and exhausted. Caregivers who successfully negotiated these barriers felt that they encountered additional barriers in the dental care setting, including long waiting times and judgmental, disrespectful, and discriminatory behavior from staff and providers because of their race and public assistance status.

Conclusions. Current proposals to solve the dental access problem probably will be insufficient until barriers identified by caregivers are addressed. (*Am J Public Health.* 2002;92:53-58)

Professional groups, expert panels, and consumer advocates have speculated that other barriers to the receipt of dental care exist, including the low priority that caregivers give to dental services, their lack of experience and ineffectiveness in using the dental care system, their inability to get time off from work, and prejudice regarding cultural background and the receipt of Medicaid that is experienced in the course of obtaining care.^{4,10-12} Information suggests, however, that once access is realized, caregivers generally are satisfied with their experiences in the dental care setting.⁷⁻⁹

These previous findings did not provide information about the problems caregivers face in gaining access to dental care in sufficient depth to devise effective interventions to meet demand. The purpose of this study was to gain insights into the experiences, attitudes, and perceptions of a racially and ethnically diverse group of caregivers regarding barriers to dental care for their Medicaid-insured children.

METHODS

Because our focus was on caregivers who would be most knowledgeable about prob-

lems of access to dental care, we chose to study those who had sought dental care for their children. We used the focus group technique to collect information from them because it is suitable for exploring previously underresearched and sensitive topics.¹³⁻¹⁵ The synergy of the group often helps in bringing out important information that would otherwise remain dormant.^{13,14,16}

Sample

Criterion-purposive sampling, which refers to the selection of information-rich cases for in-depth study,¹³ was used to identify focus group participants in 4 racial/ethnic groups (White, African American, Latino, and American Indian). To be eligible for this study, participants had to (1) be primary caregivers of Medicaid-insured children who were enrolled in Medicaid for at least 12 months prior to the study, (2) report a time during the past year when they had sought dental care for their Medicaid-insured children but either experienced difficulties in obtaining it or could not get it at all, and (3) reside in geographic areas with relatively large numbers of ethnically and racially diverse populations. We also

were interested in drawing the sample from areas with safety net providers, both public and private, who receive more than \$10 000 in Medicaid reimbursements, a figure established by a state expert panel to indicate active participation in the Medicaid program.⁵ This last criterion was used to help eliminate dental supply as a potential source of difficulty in access.

Recruitment and Procedure

We targeted caregivers in 3 geographic areas of North Carolina that met selection criteria. Potential participants were screened for eligibility and recruited into the study by staff in health departments, Head Start centers, churches, and minority organizations. From a pool of caregivers, we randomly selected the names of 10 to 15 potential participants, who were invited to take part in the study. Follow-up letters by each local coordinator confirmed the arrangements for focus groups. Prior to the start of focus groups, the primary investigator screened participants to ensure their eligibility.

A \$20 incentive was offered to each individual for participating. Focus group sessions lasted about 90 minutes, and the group comprised people of the same racial and ethnic backgrounds. The primary investigator was present at each focus group, serving either as the group interviewer or as an assistant.

We used an open-ended interview guide approved by the institutional review board of the University of North Carolina School of Public Health. Questions in the interview guide were developed on the basis of previous studies of caregivers enrolled in Medicaid⁷⁻⁹; they covered such areas as caregivers' experiences with accessing dental care, perception of barriers, consequences of such barriers, and the identification of any relevant ethnic or racial issues. The content validity of the interview guide was established through reviews by experts knowledgeable and experienced in dental public health, health behavior, and consumer advocacy.

Data Collection Procedures

Data collection and management followed the procedures outlined by Krueger.¹⁴ Sessions were taped in their entirety and transcribed. An assistant interviewer was present

for all focus groups, taking notes and observing nonverbal communications. The interviewer and assistant summarized key points throughout each group session and asked participants if the summaries were accurate. Debriefing meetings between the interviewer and assistant were held immediately after each focus group to note common opinions and perceptions expressed by the participants. A summary of each debriefing was prepared and verified for accuracy by the assistant interviewer.

Data Analysis

Qualitative content analysis was used to analyze information.^{13,14} The primary investigator assembled and analyzed all available data, which included field notes, summary reports, and transcriptions of focus groups. As transcripts became available, the investigator simultaneously listened to the tapes and checked for completeness of information. A comprehensive content review of all data, including line-by-line analysis and coding of transcripts, was conducted. Relevant themes and categories were extracted on the basis of the most frequent comments and those responses expressed with special intensity or depth of feeling.^{14,17} Research team members reviewed transcripts, assessing the accuracy of results and interpretations made by the primary investigator.

RESULTS

Eleven focus groups with 77 caregivers, predominately mothers, were conducted within a 3-month period in 2000. Four of the groups were African American (25 participants), 3 American Indian (21), 3 Latino (23), and 1 White (8). Three major themes emerged related to barriers in obtaining dental care.

Theme 1: Perceived Barriers

In response to the question "What difficulties have you experienced in getting needed dental care for your children?" 2 major categories emerged: perceived barriers associated with access (first 3 items listed below) and perceived barriers related to the quality of the experience in the dental care setting (last 4 items; Table 1).

TABLE 1—Perceived Barriers to Obtaining Dental Care as Related by Caregivers of Medicaid-Insured Children

A. Access barriers to dental care
· Difficulty in finding a provider
· Appointment-scheduling difficulties
· Inconvenient and unreliable transportation
B. Quality-of-experience barriers in dental care setting
· Excessive wait times
· Demeaning interactions with front-office staff
· Negative interactions with dentists
· Discrimination because of Medicaid

Difficulty in finding a provider. Many participants expressed frustration with unsuccessful attempts to obtain a dental visit. A mother commented, "A problem that I experienced was that I could not get a dentist to take Medicaid. I got the book out, the telephone book, and I went through about 10 to 15 dentists and no one wanted to take Medicaid. And you know that's a problem. I just gave up!"

Difficulty in scheduling appointments. If caregivers were able to locate a dentist who accepted Medicaid, they faced the next major obstacle, scheduling appointments. For many, the experience was described as both aggravating and stressful; as one explained, "It is so stressful and hard trying to get [the children] there for their first visit." Scheduling appointments was reported to be a very difficult task, often requiring a waiting period of 3 months or more. One woman stated, "One of the problems that you encounter with Medicaid children is getting an appointment in a timely manner, because once they find out that you are on Medicaid, it's like they put you on a back burner."

Participants voiced frustrations with not having a choice over scheduling appointments. One mother reported, "They only took one Medicaid patient out of each family a day. So, if I wanted to take both my children, I couldn't have done it on the same day."

Inconvenient and unreliable transportation. After caregivers succeeded in making appointments, they encountered problems in arranging transportation to get to the dental office. Most caregivers did not own a car, and they had to rely mostly on free transportation provided by social services. How-

ever, this transportation was considered by focus group participants to be both unreliable and inconvenient. Being late for the appointment, or not making it at all, was always a real possibility.

Excessive wait times. Once at the dental care site, whether public or private, families encountered other barriers (Table 1). Excessive wait time was viewed as a serious barrier. Participants described typical waits of 2 to 4 hours for routine, nonemergency care. Several discussed their distress about the wait. One mother said, "People were just leaving, walking out because it doesn't make sense for you to wait that long. That's uncalled for."

Other participants expressed outrage about the excessive waits that only they as Medicaid patients had to endure. As one participant said, "While everybody else is going ahead of you, you're still sitting there. You checked in at 10 in the morning, same time that person did, and it's 4 before you can get seen because you're on Medicaid and they are not. They're paying cash or check. It's just the way it makes you feel. I've sat 5, 6 hours once. I'll never do it again!"

Demeaning interactions with front-office staff. Participants across the focus groups described negative interactions with the front-office personnel. Because of the perceived rude behavior of staff, families described their experiences in the dental office as demeaning and degrading. The front-office staff was described consistently as disrespectful, judgmental, and insensitive. Referring to the front-office staff, participants made such comments as "They don't care if you wait," "They prejudge because of who you are," "They roll their eyes at you," "They think you're beneath them just because you get Medicaid," and "They make you feel like you're worthless."

Participants complained that dental receptionists made negative comments about Medicaid in the presence of other people. Participants in several focus groups related instances in which staff would talk so loudly that the patients' Medicaid status was constantly exposed; others described how staff handled their Medicaid cards: "Snatch it out of your hand," "Hold it up like it's contaminated," "Throw it on the floor," and showing an attitude that said "Come fetch this."

These feelings and perceptions created strong barriers, discouraging some families from using dental services for their children altogether. "You have to hold back your tears," said one mother. Another participant said, "When they do you like that, it causes you to have low self-esteem and it causes you to not ever want to go back to them again."

Negative interactions with dentists. Having surmounted the barriers associated with getting an appointment, and then interactions with staff, participants reported having to overcome a new set of barriers stemming from the provider's behavior and attitude. They cited specific incidents that caused them to be dissatisfied with the interpersonal aspects associated with obtaining care. A major barrier shared by many participants was the perception that they received "inferior," "second-class" care and were treated with a lack of respect because of their public assistance status. Participants used the words "rushed in, rushed out," "assembly line," "impersonal," and "poor" to characterize the quality of this interaction with the dentist. Some reported that dentists were not patient with their children, that "they are not children-oriented" and that "they don't pay attention to what they are doing." Participants in one focus group commented that they had formed the impression that dentists did not really want to treat their Medicaid-insured children, that "they really act like they had to pay for that appointment themselves." Several believed that dentists did not want to touch their children because "they are dirty." As one caregiver mentioned, "They [dentists] act like they don't want to touch you, you know, like something will hurt them if your hand touches them."

Some participants expressed concern that dentists did not take enough time with them to explain their children's dental care needs or to provide health education, information they felt they needed to take good care of their children's oral health. Some commented that dentists did not want to hear their questions or be bothered. As one participant said, "They automatically think that you are incompetent, that you are stupid, that you just don't know. And they don't want to hear your questions. They don't want to explain it to you in a form that you can understand. You're

not supposed to ask questions. You're just supposed to take it."

Discrimination because of Medicaid. Participants felt that they were treated differently because of their reliance on Medicaid. Overall, participants felt anger and resentment toward what they believed was discrimination against them and their children for being enrolled in Medicaid. Participants across the focus groups believed that there was a bias in favor of cash and private insurance patients, who they felt obtained better care. Some complained that their children were seen on a particular day of the week or month, and then sometimes on a walk-in-only basis. A mother said, "I don't see why they have to put Medicaid people on a walk-in-only basis on one day a week, which I think is treating you like discrimination of a sort, you know? Because I've had that happen. It makes me ill. It makes me ill." Participants in many of the focus groups commented that at one time or another they had had private insurance. They noticed a marked discrepancy between how they were treated as Medicaid patients and how they were treated with private insurance or with cash payments.

Participants spoke about being stereotyped and the stigma attached to Medicaid. Some felt they were labeled as uneducated and unemployed. For some caregivers, the stigma was a hurtful, painful experience, affecting their self-esteem to a point that they would be discouraged about, even afraid of, going to the dentist. Participants blamed the office staff more than they blamed the dentists for most barriers associated with stigma related to Medicaid.

Theme 2: Racial/Ethnic Barriers

Latino focus groups. Latino participants in 2 of the 3 focus groups cited language problems as a major obstacle to getting dental health care for their children. Specifically, they expressed concern about not being able to speak to someone who speaks their language, both on the telephone and in person. Latino participants in one focus group felt that racial discrimination played a role in their inability to receive timely and quality care. Frustrated with a particular dentist, a Latino participant said, "Why do they work like this? If they don't work with Medicaid or

if they don't want Latinos, they should put a sign on the door—"No Hispanic people."

African American focus groups. Racial discrimination was identified explicitly as a major barrier in all 4 of the African American focus groups. Participants felt that both they and their children were treated differently because of their race. Several perceived negative attitudes on the part of the office staff; they felt they were labeled as "poor Black people who live in projects." Participants in one group had overheard dental receptionists making negative comments about Black people. Several caregivers cited specific incidents where, for example, when they presented themselves to White receptionists at the same time as a White patient, the receptionist addressed the White person first. Such stories elicited strong group reactions, prompting other group participants to nod their heads in unison, indicating they had faced similar experiences.

Participants expressed disappointment that racial bias still exists. One person said, "It's just sad. I mean, just because I'm on Medicaid and just because we're Black doesn't mean we're any less of a person. It's sad." One African American man talked about the stares of people he noticed upon entering a private office in a predominantly White neighborhood. He also spoke about hurried service so as to avoid his creating "problems in the office." One participant said in frustration, "I try to teach my children all the time color is not important, but how can I teach them that and they learn from that, if they are going out here and people are treating them differently because of the color of their skin?" One woman commented that although the dental office where she takes her grandchildren sees a large number of Blacks, it does not have a Black person working there.

American Indian focus groups. Racial problems also were mentioned by 2 of the 3 American Indian groups. Several participants felt that they were treated differently because they were American Indian. However, the racial problems described here did not appear as formidable as those described by African American focus groups.

White focus group. There were no reports of ethnic or racial problems affecting families in the White group.

Theme 3: Consequences

The study revealed 2 categories of consequences stemming from barriers that families encounter in obtaining dental care for their children. One category is child related, whereas the other pertains to families.

Child-related consequences. These consequences included children's missing school because of appointment restrictions imposed by the dental system and transportation difficulties. Several participants also cited persistent pain from tooth decay, which had gone untreated because they could not get timely appointments for their children.

Several participants also spoke about psychological consequences affecting their children. Because of tooth discoloration or decay, the children of some caregivers felt embarrassed, especially at school. Two participants reported that their children were ridiculed by other students because of poor dental appearance. Participants in several groups felt that their children suffered from low self-esteem because they also were aware that they were being treated differently. One mother quoted her 8-year-old daughter as saying, "How come I'm getting treated differently?"

Family-related consequences. The numerous obstacles caregivers confront in trying to access needed dental care for their children often result in enormous stress and pressure, described by participants as enough to "discourage" them from trying to access such care. Many participants complained about the amount of time and energy required in obtaining dental care for their children. One distressed mother, referring to the whole process of seeing a dentist, said, "They give you all kinds of obstacles that you have to go through for your child to be seen and you finally give up." Many single mothers complained of having to work, raise children single-handedly, and balance day-to-day necessities. Dental appointments were viewed as "frustrating," some commenting that if they could, they would "avoid" taking their children to the dentist.

Many participants also described the emotional toll in dealing with barriers faced inside the dental office. They complained of feeling "powerless" and reluctant to complain about the practices and policies of the dental office or of the dentist, fearing reprisals in the form

of being dropped as patients. Several indicated that they often felt as if they were "at the mercy" of dentists. Some participants spoke of being blamed by the dental staff for their children's dental problems—this in light of the fact that they had tried unsuccessfully to obtain care.

Participants expressed hurt because of discrimination. "It hurts the way they treat you," said one grandmother. One mother stated she felt like "pure dirt" having to see her daughter experience low self-esteem as a consequence of waiting for months for the dentist to treat her badly aligned tooth. Some participants experienced low self-esteem themselves as a result of interactions with the dental office staff. One mother said that the whole process of trying to obtain dental care was "humiliating" and that "it takes a toll on the family."

DISCUSSION

Several limitations must be considered when interpreting the results of this study. First, information gathered from focus groups represents the attitudes and perceptions of a narrow sample of the population. Without further inquiry, generalizations regarding larger populations must be avoided. Second, the individuals we sampled, who had a prior disposition to use dental care, encountered barriers and thus were generally dissatisfied with the dental care experiences of their children. Therefore, the findings may overestimate the severity and prevalence of access barriers and levels of dissatisfaction that actually exist within the broader Medicaid population. It is worth noting, however, that our study included 4 racially and ethnically distinct groups. According to local recruiters, there were many more eligible families who met the selection criteria. Variations in responses were minimal. Recurrence of themes across focus groups suggests that we captured experiences and perceptions common to a diverse group of Medicaid caregivers. A third possible limitation is that participants might not have provided truthful and comprehensive answers to the questions posed. Because of the detailed information collected from focus groups and the consistency in responses, we do not suspect that this limitation is significant.

To our knowledge, this is the first study to provide an in-depth investigation aimed at gaining insight into the perspectives of caregivers who encountered difficulties in trying to obtain dental care for their Medicaid-insured children. Numerous barriers at different points awaited the sample of low-income caregivers as they sought dental care for their Medicaid-insured children. Our study reveals that from the time dental care was sought to when it was actually received, caregivers had to negotiate a series of barriers. Barriers associated with access and the quality of the experience at the dental care setting made, individually or in concert, access to care a difficult process, resulting in delayed care or an unsatisfactory experience. In some instances, such barriers thwarted access altogether.

Our findings build on previous research results. Using focus groups, we obtained a deeper understanding of some of the previously identified barriers. Participants, across the board, shared experiences of their children's failed access to dental care. They discussed the great deal of energy and time that they must devote to getting needed dental care for their children—personal commodities that are often in short supply because of the daily challenges confronting our sample of low-income families, especially single mothers, who formed the majority of focus group participants. Participants expressed a wide range of emotions, from despair to anger to disappointment, in describing a health care system that, in their words, is not sensitive or responsive to their needs or to those of their children.

Our study identified a new set of barriers and issues not previously reported, thus paving the way for future research to assess their validity, magnitude, and effect. One troubling finding is the presence of barriers at the dental care setting. In this regard, our findings do not support previous studies' conclusions that once children and their caregivers gain access, they generally are satisfied with the quality of care they receive.⁷⁻⁹ Among the focus groups, there was a perception of discrimination based on race and being on Medicaid; of the two, prejudices against Medicaid were believed to be more prevalent and severe. According to the participants, using Medicaid as the source of payment largely ex-

plains the presence of barriers such as excessive wait times, negative interactions with front-office staff, and the delivery of dental care that they perceived as inferior and substandard.

Participants in focus groups considered the demeaning and discriminatory attitude and behavior of front-office personnel as a major barrier. To avoid encountering such attitudes and behaviors, some participants often postponed or canceled dental visits. A paucity of research exists related to the attitudes and behaviors of front-office personnel toward low-income patients and how these may raise barriers to dental care. Lam et al.⁶ concluded that attitudes and beliefs of front-office personnel toward Medicaid clientele could be discriminatory, thus having a negative impact on young children getting dental care. Further research is needed to assess to what extent attitudes and behaviors of the front-office staff inhibit use of dental services by families of Medicaid-insured children.

Our study generated findings that have not been observed in previous studies. Many participants were dissatisfied with the attitudes and behaviors of dentists, describing them as impersonal and disrespectful. Regardless of their racial/ethnic background, caregivers reported discrimination by dentists because of their Medicaid status.

The quality of the provider–patient relationship is an important factor that influences utilization.¹⁸⁻²⁴ Donabedian suggested that negative relationships in the interpersonal process of the delivery of care by the provider can result in lower rates of utilization.¹⁹ Furthermore, because some dentists perceive poor patients as uncooperative and unappreciative, they may provide abrupt and impersonal care.²⁰ Our findings show that some participants elected not to return to offices where they perceived negative attitudes and behavior on the part of the dentist. Our findings require further research to explore possible prejudice in the dental care setting toward low-income individuals and those on Medicaid.

Except in the White focus group, ethnic and racial barriers were identified in the dental care setting. Until now, evidence for these barriers has been speculative and has addressed the role of the dentist only.^{12,20,23} Par-

ticipants felt racial bias was more prevalent among office staff than from the dentist.

More than any other participants in our study, African Americans voiced complaints about racial discrimination. Our findings on racial discrimination support a widely held notion that being African American, in and of itself, constitutes a barrier to access to health care and affects the type of care received once in the system.²⁵⁻³⁰ Further research is warranted to examine racial prejudice in the dental care setting.

This study identified the multiple nonfinancial costs our sample of caregivers had to endure as they tried to overcome a set of barriers. Prior research suggests that patients seeking services within settings perceived as nonreceptive suffer psychologically, and the psychological toll in turn acts as a potential barrier to the use of health care services.²² This suggestion held true for some caregivers in our study. They reported that the emotional costs of dealing with barriers in the dental setting outweigh the rewards of getting care, thus reducing utilization.

Many of the concerns that participants expressed about their experiences in dental settings may have certain ethical implications. For example, if office staff divulged children's Medicaid status in front of other patients, then such disclosure may constitute a departure from the principle of patient autonomy enshrined by the patient's right to confidentiality. Ethical implications aside, such disclosure also may compromise one's dignity. Similarly, when dental offices limit scheduling of Medicaid patients to certain times of the day or days of the week—a practice seen as harmful and unfair by some participants—such action possibly constitutes a departure from the ethical principles of nonmaleficence and justice. Although no firm legal doctrines prohibit such practices, they had an adverse impact on the focus group participants and their willingness to seek dental care.

Overall, what is disturbing about our findings is that despite realizing access, caregivers still had to navigate some formidable barriers in the dental setting. Equally disturbing is the powerful role the front-office staff played in adversely influencing access and the quality of the experience for families in our focus groups. We believe that although

many important changes,^{5–11} such as increased rates of reimbursement and patient education, are being proposed to improve access to dental care for those enrolled in publicly financed programs, these changes will not be sufficient because they fall short in addressing some of the more vexing obstacles caregivers face in the dental setting. ■

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Contributors

M. Mofidi, who conceived, planned, and implemented the study, was the principal author and analyst of the study. R.G. Rozier and R.S. King were involved in the study design, interpretation of data, analysis, and revisions of the paper.

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